

# FRAXA UPDATE

FALL 2000

VOLUME 7, NO. 3

A PUBLICATION OF  
FRAXA RESEARCH  
FOUNDATION

"NEVER

DOUBT

that a small

group of

thoughtful,

committed

citizens can

change the

world.

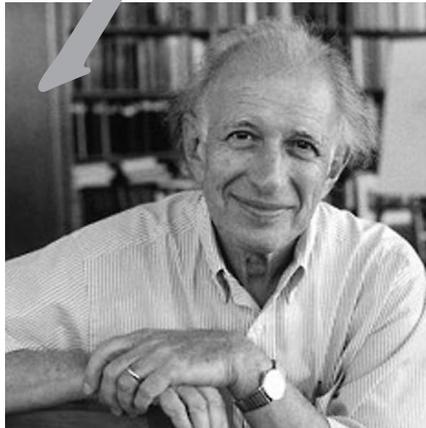
INDEED,

it's the only

thing that

ever has."

— Margaret Mead



## FRAXA Researcher Wins Nobel Prize

On October 9th, we learned the exciting news that Dr. Eric Kandel had won the Nobel Prize for Medicine, along with two other neuroscientists, Arvid Carlsson and Paul Greengard. The Nobel Assembly praised the three scientists for their work on how brain cells transmit signals to each other, and said that their work has led to a fuller understanding of how the brain functions and how neurological and psychiatric disorders may be better treated. Dr. Kandel is a University Professor at Columbia University and a Senior Investigator for Howard Hughes Medical Institute. He has written several neuroscience textbooks in wide use in medical schools across the country.

This Nobel award is exciting news for the Fragile X community because Dr. Kandel is an active fragile X researcher and a Scientific Advisor for FRAXA. In 1999, FRAXA awarded him a two-year \$300,000 grant to develop new fragile X mice in which the FMR1 gene can be switched on or off, simply by feeding the animals a common antibiotic. (See [www.fraxa.org](http://www.fraxa.org) or your Summer 1999 FRAXA Update for details). With two Nobel laureates on FRAXA's Advisory Board, James D. Watson and Eric Kandel, we are well positioned to help guide fragile X research towards effective treatments and a cure.

## NEW RESEARCH GRANTS

Great progress has been made this year: In the year 2000 alone, FRAXA's grants and fellowships for fragile X research exceeded \$1.5 million, resulting in an increasingly clear understanding of the disease on the molecular level. The remarkable breakthroughs in recent years have sparked more widespread interest in Fragile X, and new labs have joined our field. FRAXA is now working jointly with the National Institutes of Health to sponsor expanded basic research in fragile X, and the recently passed Children's Health Act will, if funded, establish major fragile X research centers (see article, page 2.)

In addition to funding research on basic mechanisms of disease, FRAXA is sponsoring investigations to test the theoretical basis for possible types of treatment. We are funding studies of gene therapy, protein replacement, demethylation, and pharmacotherapy. More work remains to be done in these areas, and we will devote much effort and many dollars to these efforts in 2001.

FRAXA is also planning to increase its focus on therapeutic strategies, especially as more money becomes available for basic science research through FRAXA's joint funding program with NIH

### Also in this issue:

- Children's Health Act Passed!

(at least \$1.4 million per year in addition to current NIH funding) and the research centers promised in the Children's Health Act. We will

*Continued on page 4*

FRAXA is a nonprofit, tax-exempt charity run by parents of children with fragile X syndrome. Fragile X syndrome is the most common inherited cause of mental retardation and developmental disabilities, affecting approximately 1 in 2000 males and 1 in 4000 females. FRAXA's goal is to accelerate research aimed at the treatment and cure of fragile X, by direct funding of promising research projects and by raising awareness of this disease.

# Report from Washington: CHILDREN'S HEALTH ACT BECOMES LAW

by David and Mary Beth Busby

On September 27, 2000, the U.S. Congress passed and sent to President Clinton the Children's Health Act of 2000, which provides research and other funding for



John Edwards (NC)

diseases and conditions afflicting millions of children. One provision of this bill directs the National Institute of Child Health and Human Development (NICHD) to "expand, intensify, and coordinate the activities of the Institute with respect to research on . . . fragile X." In addition, it requires NICHD to "make grants . . . for the development and operation of [at least 3] centers to conduct research for . . . improving the diagnosis and treatment of, and finding the cure for, fragile X".



Chuck Hagel (NE)

In a separate section dealing with pediatric research, including Fragile X, the Secretary of Health, Education and Welfare is required to enter into agreements with "qualified health professionals who agree to conduct pediatric research in consideration of the Federal government agreeing to repay, for each year of such service, not more than \$35,000 of the principal and interest of the educational loans of such professionals." President Clinton signed the bill on October 17th.



William Delahunt (MA)

We appreciate, more than we can say, the hard work of Subcommittee leaders: Senator Bill Frist (R.TN) and Sherrod Brown (D.OH) and their staffs -- along with so many others on the Hill. We particularly appreciate and honor the bipartisan help of Senators John Edwards (D.NC) and Chuck Hagel (R.NE), and Representatives



Wes Watkins (OK)



William Delahunt (D.MA) and Wes Watkins (R.OK). They are our original sponsors and champions. They listened to the thousands of Fragile X parents, families, and friends throughout the United States. They and their staffs demonstrated the political skill and the statesmanship that let us in the Fragile X community know that when children's health is concerned, the system can indeed work for the children, our nation's most precious resource.

The House of Representatives led the way by passing the first version of this legislation on May 9 by 419 to 2.

Finally, all of the hundreds of dedicated and persistent fragile X advocates who have worked so hard, calling, writing, and visiting members of Congress should thank each other. None of this would have happened without you. We would like to list each person who has helped, but there are hundreds and hundreds of you. You have done so much in just a few years.

## How Far We've Come

Now that we've had the opportunity to celebrate the recognition of Fragile X in the law of the land, let's take stock of where we are. When a group of Fragile X parents and friends met in Washington in April of 1999, the day after the Mary Higgins Clark FRAXA Gala, they defined 3 goals:

1. Educate Congress about Fragile X
2. Persuade both Congressional Appropriations Committees to ask the NIH to accelerate and enhance funding of Fragile X Research, and
3. Secure early passage into law of The Fragile X Research Breakthrough Act

We succeeded almost beyond our hopes with all three goals:

1. Because of your letters, calls, faxes, e-mails, and visits, any Member or congressional staffer who doesn't know that Fragile X is the most common cause of inherited mental impairment doesn't do his or her homework. The Resolutions in the Senate (which passed) and the House (which didn't) gave momentum to the Fragile X bill, which snowballed into its inclusion in the Children's Health Act. After some partisan bickering by the committee staffs, the Children's Health Act passed both Houses easily.
2. Both the 1999 Senate and House Appropriations Reports direct NIH to enhance Fragile X research from currently available funds. Actually, NIH has increased its Fragile X spending each year for the past 5 years. In addition, this year NIH is co-sponsoring, with FRAXA, a new funding program that invited scientists throughout the world to submit research ideas and projects. The first grants under this program will be awarded within a few months.
3. All of the operative language of the Fragile X Research Breakthrough Act was included in the Children's Health Act of 2000 as signed into law by the President.

## Finishing the Job

We need to finish the job of funding the Fragile X provisions in the Children's Health Act of 2000 which is "authorizing" legislation. Fortunately or unfortunately, project legislation of the Federal Government is a 2-stage process. First the "Authorizing Committees" authorize and guide the project through to enactment; then the "Appropriations Committees" put up the money they deem necessary for that project, taking into consideration other projects and budget limitations.

We have 2 things going for us: **momentum** and **just a small number of key members to convince**.

The **momentum** is provided by the passage of the Children's Health Act of 2000 with only petty problems and a vast majority of both Houses — plus the President's signature.

The **members we must convince** are mainly those who sit on the House and Senate Appropriations Subcommittees dealing with Health. We will not know the exact composition of the committees until Congress reconvenes in January, but it will remain almost the same. These are the key people to call, write, and visit over the coming months:

### Senate Appropriations Committee

#### Subcommittee on Labor, Health and Human Services, and Education

*Specter (PA) Chairman*

*Cochran (MS)*

*Gorton (WA)*

*Gregg (NH)*

*Craig (ID)*

*Hutchison (TX)*

*Kyl (AZ)*

*Stevens (AK) Ex Officio*

*Harkin (IA) Ranking Minority Member*

*Hollings (SC)*

*Inouye (HI)*

*Reid (NV)*

*Kohl (WI)*

*Murray (WA)*

*Feinstein (CA)*

*Byrd (WV) Ex Officio*

### House Appropriations Committee

#### Subcommittee on Labor, Health and Human Services, and Education

*Porter (IL), Chairman*

*Young, (FL)*

*Bonilla (TX)*

*Istook, Jr. (OK)*

*Miller (FL)*

*Dickey (AK)*

*Wicker (MS)*

*Cunningham (CA)*

*Obey, (WI) Ranking Minority Member*

*Hoye, (MD)*

*Pelosi (CA)*

*Lowey (NY)*

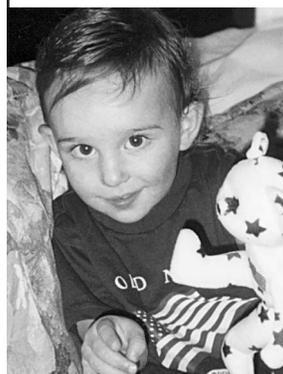
*DeLauro (CT)*

*Jackson, Jr. (IL)*

*Northup (KY)*

## Join our KEY FRAXA email list

Just send email to David Busby at [busby.david@dorseylaw.com](mailto:busby.david@dorseylaw.com) and we'll add you to the list. Or call David at 202 824 8820



## In Memory of Elizabeth Tracy

*The Tracy Family of Watertown, MA, lost their 22-month-old daughter Elizabeth in a car accident in July. They chose to direct donations to FRAXA in Elizabeth's memory to help others understand about the organization. They are familiar with FRAXA through family and friends that are involved in it. Her father Tim writes:*

*"Elizabeth was energetic and playful and had an infectious smile. She loved to go to the park and play with her Daddy on her swing. She loved playing in the pool with her Mommy and going to school at her cousin Christine's house, with Anthony and Marisa. She loved spending time with her sister Kaitlin, Nanny, Grampy, Papa, and her aunties and uncles and many cousins."*

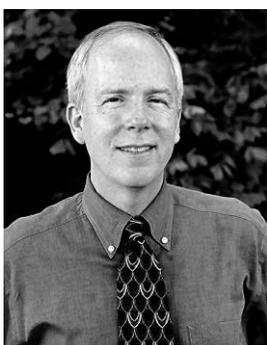
Continued from page 1

look for greater emphasis on treatment from applicants for FRAXA grants, which will be available in greater amounts (we originally started with \$25,000 postdoctoral fellowships; there is now no limit on investigator-initiated grants, and some current awards approach \$200,000 per year).

Two studies just funded by FRAXA focus on children with fragile X, as we attempt to bridge the gaps between molecular studies and how the brain works in affected individuals. Descriptions by the investigators follow.

For a complete listing of all currently funded projects, please visit [www.fraxa.org](http://www.fraxa.org) or contact FRAXA. When you receive this newsletter, new applications for FRAXA's December 1st deadline will have arrived; the new awards will be announced early in 2001. If you or your group or company would like to sponsor one of these research grants or fellowships, please call Katie Clapp at FRAXA to learn about the various options.

## Entering Middle School with Fragile X Syndrome



**DON BAILEY, PH.D.**

University of North Carolina at Chapel Hill

\$30,000 interim funding from FRAXA; the National Fragile X Foundation is providing an additional \$10,000 for this project.

*by Don Bailey*

The Carolina Fragile X Project has been following a longitudinal sample of children with fragile X syndrome since the preschool years. The oldest children in the study are now ready to enter middle school. This grant provides one year of interim funding to maintain contact with the families in the study and, in combination with other funding sources, to conduct one annual assessment for each of 67 students. The study will assess the academic and adaptive skills of students with fragile X as they enter middle school, the extent to which they participate in and feel a sense of belonging to school and community groups, and the extent to which they develop social relationships with other children. For those children who enter middle school this year, we will also interview families to find out more about the challenges associated with that transition.

## Neural Network Model of Working Memory in Those with Fragile X Syndrome



**MINA C. JOHNSON-GLENBERG, PH.D.**

Waisman Center, University of Wisconsin, Madison, \$67,000

*by Mina C. Johnson-Glenberg*

This study will attempt to bridge one of the gaps between neurology and behavior. Based on the research regarding hippocampal size and differences in the dendrites and spines of those with fragile X syndrome, I will be researching how long-term and working memory interact in two different populations. A computational neural network will be created to simulate memory processing leading to a finer-grained model of the information processing style and cognitive capabilities of those with fragile X. To this end, I have designed a working memory sequential memory task that feels like a card game. Long-term and sequential working memory will also be assessed in a typically developing mental age match group. A neural network model that simulates the interplay of hippocampal and prefrontal memory in typically developing children will first be created. Parameters in the typically developing model will be adjusted until the pattern of results mimics the results of those with fragile X.

Neural networks are powerful tools that can provide insights into the particular strengths and weaknesses found in the fragile X cognitive profile. Analyzing such models can help to guide the development of remediation programs and provide neurologically theory-driven explanations for various cognitive deficits (e.g., why individuals with fragile X have such trouble learning to read in the usual sequential phonemic manner).

## Finding New Researchers for Fragile X

Each year, over 25,000 scientists converge on one city for the Society for Neuroscience annual meeting. This year, in New Orleans, investigators who stopped by FRAXA's display booth were gamely recruited to the fragile X field by "Dr. Mike" Tranfaglia, Debbie Stevenson, and Katie Clapp, and as a result, we expect more applications on December 1st. Many current FRAXA investigators presented their latest research at this meeting.

# National Fragile X Foundation Update

By Robert Miller

Following our recent and highly successful 7th International Fragile X Conference, at which approximately 600 families and professionals gathered to share and discuss the latest research findings and therapeutic interventions, we immediately began work planning the 8th International Conference to be held in Chicago July 17 - 21 in 2002. The lessons learned and the feedback gained in Los Angeles will be used to make that event even more helpful for FRAXA and NFXF members alike.

The National Fragile X Foundation began in 1984 under the leadership of Dr. Randi Hagerman. Since its inception the foundation has helped thousands of families and professionals by providing relevant and up-to-date information covering all facets of fragile X syndrome. Our mission is to provide education, increase awareness and support research. Our international and regional conferences, 38 affiliated resource groups and centers, internet site, quarterly newsletter, books, videotapes and audiotapes (currently 18 titles) as well as our toll-free telephone line and email response system allow us to address the immediate needs of parents, teachers, therapists and medical staff. In addition, our resource-mapping project is designed to make sure that the NFXF's resources are pertinent and comprehensive. Currently, we are developing a database of all fragile X resources that the NFXF maintains, while one of the recipients of our fellowship funding tabulates and analyzes the results from the over 450 responses to our national needs assessment. Our website, [www.FragileX.org](http://www.FragileX.org), is also going through a major revision with the goal of making it even more comprehensive, and easier for families to find the information they need.

We hope you will want to learn more about the National Fragile Foundation and we appreciate the opportunity that Katie Clapp and the FRAXA Board have given us in this newsletter. You can reach us at 1-800-688-8765, at [NATLFX@sprintmail.com](mailto:NATLFX@sprintmail.com) or at PO Box 190488 / San Francisco, CA 94119.

## PREIMPLANTATION GENETIC DIAGNOSIS (PGD) IS NOW A POSSIBILITY FOR SOME FRAGILE X CARRIERS

by Debbie Stevenson

The Reproductive Genetics Institute in Chicago is now doing Preimplantation Genetic Diagnosis (PGD) for Fragile X. This means that couples who are carriers could screen their embryos for Fragile X before becoming pregnant. It's a new technology that the Reproductive Genetics Institute has created to test for Fragile X. The only other place currently offering PGD for Fragile X is in Brussels, Belgium. The process used by the Institute was created by Dr. Yury Verlinsky. The Reproductive Genetics Institute specializes in genetic testing, and they have been doing PGD for many other disorders since 1990. PGD for Fragile X is a new technology for them, but so far has been successful.

The process involves in vitro fertilization. First, the woman takes fertility drugs to increase the number of eggs produced in a cycle. After the eggs are retrieved and fertilized with the man's sperm, resulting embryos are tested for Fragile X and non-Fragile X embryos are then replaced in the woman's uterus. In many cases, it is possible to work with a local doctor, which works well since there is much monitoring involved throughout the process. When the eggs are ready for retrieval, the Institute will send a technician (at your expense) who takes the biopsy of the embryos and sends them to Chicago to be tested. Alternately, you can travel to Chicago for the retrieval and stay there through the embryo transfer process.

Not all families are accepted into the program. The Institute tests for Fragile X by establishing genetic markers on as many members of the immediate family as possible, which allows them to detect which embryos have Fragile X and which ones do not, on about day three after the eggs have been fertilized. Some families aren't considered "informative enough" and are not eligible for PGD. This means that there are not enough differences in the family's DNA to establish genetic markers that can accurately distinguish Fragile X embryos from non-Fragile X embryos. The more genetic markers the Institute is able to identify, in most cases, the higher the rate of accuracy they can achieve.

The process is safe for the embryos because only genetic material, called polar bodies, that embryos naturally discard is tested. Also, since some Fragile X female carriers go through early menopause, not all women within child-bearing years are able to make the IVF process successful.

My husband and I went through this process, and we are expecting a Fragile X-free child in April. The results of the PGD were recently confirmed through Chorionic Villus Sampling. It's a good idea for anyone who does achieve pregnancy to confirm the PGD results through either amniocentesis or Chronic Villus Sampling. I would be happy to talk to anyone who would like to consider this option for becoming pregnant. I also have a list of recommendations to make the IVF process more successful for female carriers of Fragile X. My phone number is (212) 828-1883 and e-mail is [dstevenson@pop.net](mailto:dstevenson@pop.net). To contact the Reproductive Genetics Institute, contact Christina Masciangelo at (773) 296-7095.

# FRAXA EVENTS

## Fundraising for FRAXA

Have you ever read the newsletter and wondered where all the grant money our researchers receive comes from? It comes from YOU! None of this would be possible without the people who are dedicated to helping raise funds for FRAXA. So if you have any idea for a fundraiser in your community - big or small — FRAXA would be grateful for the help. Even a few hundred dollars is meaningful! Anything is possible — from a garage sale to a dressy dinner party to a letter to family and friends, asking that they donate to FRAXA instead of giving you that new tie or scarf at holiday time. Anything goes! If you would like to talk about your ideas, or if you would like to see samples of invitations, etc. that others have used successfully, call Debbie Stevenson at 212-828-1883, email [dstevenson@pop.net](mailto:dstevenson@pop.net), or Katie Clapp at 978-462-1866, email [kclapp@fraxa.org](mailto:kclapp@fraxa.org).



MC Brian Banmiller, KTVU, Linda and Tom Leonard and Marvin

## Fix Fragile X Fundraiser Debut A Big Success

by Dean Clark

In August, the Clark and Leonard families hosted the "Fix Fragile X" Fundraiser in San Ramon, California.

The Clarks' three year old son Lucas, also the Leonard's grandson, has Fragile X.

This was the first fundraiser the Clarks and Leonards have hosted and it was quite a success, raising approximately \$145,000. All net proceeds of the event will be dedicated to "fixing" Fragile X, and will be evenly divided between FRAXA and the M.I.N.D Institute.

The fundraiser was also instrumental in promoting awareness. Stefanie Clark appeared in a local newspaper in an article about Fragile X and the festivities. The Clarks and Leonards appeared live on KTVU Fox "Mornings on 2".

Over 200 people joined in for the evening of silent and live auctions, dining, and dancing to the tunes of Marvin and The Outcasts.

## 4th Annual Fragile X Golf Benefit

by Leslie Bagdasarian

The Fourth Annual Fragile X Golf Benefit and auction was held on Monday, July 17 at Acacia Country Club in Lyndhurst, Ohio. This year we raised a record \$104,000!

We had a beautiful, sunny day for the Shotgun Start with 152 golfers from as far as Florida and Texas. Following the golf, participants visited our Silent Auction of over 125 items. Herb Score, former radio voice of the Cleveland Indians, and his wife, Nancy, returned as our hosts and auctioneers for the evening.

Our dinner program included addresses by Rod Tyler, parent, golf coordinator and trustee, Richard Haase, parent and trustee, and Leslie Bagdasarian, President of the Fragile X Alliance of Ohio. FRAXA's video "Unlocking Fragile X" made a visible impression on the audience. Our guest speaker was Dr. Huntington Willard, Chairman of the Human Genetics Department at Case Western Reserve University and Chairman of the University Hospitals Research Institute in Cleveland. Dr. Willard, an internationally-known X chromosome researcher, spoke of the importance of genetics research and how events like this provide a link from the scientific lab to the affected families. He suggested that we try to make Fragile X Cleveland's special disease! Dr. Willard was instrumental in founding the Fragile X Alliance of Ohio, and so we were thrilled he was able to join us this year.

Our core committee of Leslie and Ara Bagdasarian, Maryanne and Rick Haase, Jill Maksoudian, Jeanne and Mike Sydenstricker, Rod Tyler and Jim Vitalie are to be commended for a job well done. Because of their hard work, and the help of



Dr. Huntington Willard speaks to the dinner audience

numerous volunteers, the Fragile X Alliance of Ohio is able to make a major contribution to FRAXA. Part of this amount will go to fund the grants of Dr. Alan Tartakoff here at Cleveland's Case Western Reserve University.

If you would like a copy of our program or have any questions, please email Leslie at [lbgdas@oh.verio.com](mailto:lbgdas@oh.verio.com).

## 26.2 Miles Towards a Cure

by Leslie Eddy

On Nov 5, my husband, my sister and I joined an extremely ambitious group of Irish runners in taking the ultimate challenge...to complete the New York City Marathon. The idea originated from a group of Fragile X parents in Ireland who decided they wanted to gather a team together to complete the 26.2 mile race and raise money for Fragile X.

The New York City Marathon is among the largest marathons in the world, attracting over 30,000 runners. It is also one of the most difficult marathons to enter because of its notoriety. Runners must apply through a "lottery system," which offers no guarantee of an entry spot. Alan Tate of Ireland orchestrated an incredible opportunity to raise awareness and funds: Alan brought together a team of 22 runners from Ireland and the United States, each of whom agreed to try to raise \$4,000 for Fragile X. Alan secured spots for the entire Fragile X team, and so everyone met in New York City to show support and devotion to a cause close to home.

The Fragile X T-shirts Alan's team designed helped us spread the word. Runners and fans alike asked questions about Fragile X, and a few of us encountered other runners who, like us, had children affected by Fragile X.

Knowing that Alan, his 21-year-old Fragile X son, and his cousin all completed the marathon made it worthwhile. While funds are still being collected, the event is likely to bring in close to \$85,000 for fragile X.



### The Glass Family Fundraiser

By Lori Glass

My husband and I were looking for a way to raise money for FRAXA. We decided that the most effective way for us was to make an annual appeal to our friends and family. So, we mailed letters describing Fragile X and the need for research funds. We were overwhelmed with responses and good wishes for our son's future. So far, we are happy to have collected checks for \$2,660.

It was my husband's idea to send out letters. He encouraged me not to feel uncomfortable asking close friends for money. After the response, it has been a very positive experience. We would recommend this approach to all parents, grandparents, aunts, uncles and friends of an affected person.

Take the time out now and start your own fundraiser. It will give you the sense that you are contributing to the ultimate benefit of finding a cure for your loved one. Just imagine if all of us took it upon ourselves to do the same, how much further along the search for a cure would be.

## Available from FRAXA

All prices include shipping within the U.S. Please call or e-mail for international orders.

### FRAXA CD-ROM

One CD-ROM holds FRAXA's video "Unlocking Fragile X" (MPEG format), two years of newsletter issues, fragile X articles and FRAXA's brochure (Acrobat format). Works with PC or Macintosh computers. \$5

### FRAXA "X" Lapel Pin

Gold-plated FRAXA logo pin is a wonderful gift! \$10

### Unlocking Fragile X

An emotional, inspiring look at fragile X, FRAXA and current research, with author and grandmother Mary Higgins Clark, Nobel-Prize Winners James D. Watson, Ph.D, and Eric Kandel, MD, and many others. This 10-minute video is a great fundraising aid. \$8

### FRAXA Tribute Cards and Memorial Cards

Both are available in packages of 10 cards for \$30.

### FRAXA T-Shirts

White, all-cotton T-shirts feature FRAXA's logo on left chest. Adult sizes: M, L, XL, XXL. Great gift! \$12

### Fragile X: A to Z

Edited by Wendy Dillworth, this is chock full of stories from daily life with fragile X children. Browse through helpful suggestions on topics such as adolescence, bike riding, and dental work. 73 pages, \$15.

### A Medication Guide for Fragile X

By Michael Tranfaglia, MD, Psychiatrist and Parent. This guide helps parents and others understand behavioral symptoms of fragile X and the medications commonly prescribed to help manage these symptoms. \$20.

#### HAVE YOU HEARD OF FRAGILE X?

Our loved one has Fragile X  
Fragile X is an inherited genetic disorder  
2000 boys and 1 in 4000 girls. It can cause  
• mental impairment ranging from learning to mental retardation  
• behavioral challenges, like anxiety & I  
• autistic-like behaviors, such as hand-

#### YOU CAN HELP

Please understand that new situations will cause our loved one to become anxious and afraid. Often, neither we nor (s)he can control this behavior. So please be encouraging and just

Smile!

For More Information  
FRAXA Research Foundation  
45 Pleasant Street, Newburyport, MA 01950  
web: <http://www.fraxa.org>

### Fragile X Information Cards

Many families have asked for a card that they can give to people who have no knowledge of fragile X. Business-size cards: \$10 per 100.

### Free: FRAXA Brochures and gift envelopes

# FRAXA POSTDOCTORAL FELLOWSHIPS REQUEST FOR GRANT APPLICATIONS

## Upcoming Deadlines: May 1, 2001 and December 1, 2001

FRAXA offers fellowships and grants to encourage research aimed at finding a specific treatment and ultimate cure for fragile X syndrome:

- Postdoctoral fellowships of up to \$35,000 each per year
- Investigator-initiated grants for innovative pilot studies aimed at developing and characterizing new therapeutic approaches (no funding limit)

FRAXA is particularly interested in preclinical studies of potential pharmacological and genetic treatments for fragile X and studies aimed at understanding the function of the FMR1 gene. Applications are accepted twice each year. Information is available at [www.fraxa.org](http://www.fraxa.org) or by contacting FRAXA.

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MARK YOUR CALENDAR NOW FOR

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## THE FOURTH ANNUAL MARY HIGGINS CLARK GALA

TAVERN ON THE GREEN, NEW YORK CITY  
THURSDAY, MAY 3RD, 2001

MASTER OF CEREMONIES: ROGER MUDD

CO-CHAIRS: MARY JANE CLARK  
AND MARGARET ANN BEHRENDIS

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## THE FIRST FRAXA TEXAS GALA

AUSTIN, FRIDAY MAY 18TH

WITH SPECIAL GUEST MARY HIGGINS CLARK

CHAIR: CLAUDIA BURNETT

*Please contact FRAXA if you would like invitations to either of these events or if you can help us recruit sponsors.*

**FRAXA**  
RESEARCH  
FOUNDATION

45 Pleasant Street  
Newburyport  
Massachusetts 01950

# FRAXA UPDATE

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# PLEASE HELP

# FRAXA

in supporting research aimed  
at treatment for fragile X RESEARCH  
FOUNDATION

FRAXA is a national 501(c)(3) tax-exempt organization. Every penny you donate goes to research: FRAXA has specific grants to cover all overhead. Supporters receive this newsletter and are welcome to participate as active volunteers.

## Yes, I would like to help FRAXA

- Member (\$25+)       Benefactor (\$500+)  
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 Sponsor (\$100+)       Named Research Fund (\$5000+)  
 Named Research Chair (\$25,000+)

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